

Award Number: W81XWH-11-2-0213

TITLE: Family Caregivers for Veterans with Spinal Cord Injury: Exploring the Stresses and Benefits.

PRINCIPAL INVESTIGATOR: Susan Charlifue, PhD

CONTRACTING ORGANIZATION: Craig Hospital
Englewood, CO 80113

REPORT DATE: December 2017

TYPE OF REPORT: Final

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;

Distribution Unlimited

The views, opinions and/or findings contained in this report are those of the author(s) and should not be construed as an official Department of the Army position, policy or decision unless so designated by other documentation.

REPORT DOCUMENTATION PAGE				Form Approved OMB No. 0704-0188	
Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing this collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Department of Defense, Washington Headquarters Services, Directorate for Information Operations and Reports (0704-0188), 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302. Respondents should be aware that notwithstanding any other provision of law, no person shall be subject to any penalty for failing to comply with a collection of information if it does not display a currently valid OMB control number. PLEASE DO NOT RETURN YOUR FORM TO THE ABOVE ADDRESS.					
1. REPORT DATE December 2017		2. REPORT TYPE Final		3. DATES COVERED 30Sept2011 - 29Sept2017	
4. TITLE AND SUBTITLE Family Caregivers for Veterans with Spinal Cord Injury: Exploring the Stresses and Benefits				5a. CONTRACT NUMBER	
				5b. GRANT NUMBER W81XWH-11-2-0213	
				5c. PROGRAM ELEMENT NUMBER	
6. AUTHOR(S) Jennifer Coker, MPH Susan Charlifue, PhD E-Mail: jcoker@craighospital.org ; Susie@craighospital.org				5d. PROJECT NUMBER	
				5e. TASK NUMBER	
				5f. WORK UNIT NUMBER	
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) Craig Hospital 3425 S. Clarkson Street Englewood, CO 80113				8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012				10. SPONSOR/MONITOR'S ACRONYM(S)	
				11. SPONSOR/MONITOR'S REPORT NUMBER(S)	
12. DISTRIBUTION / AVAILABILITY STATEMENT Approved for Public Release; Distribution Unlimited					
13. SUPPLEMENTARY NOTES					
14. ABSTRACT When family caregivers are unable to cope effectively with all role responsibilities, the health and well-being of the care recipient also may be jeopardized. Unfortunately, there are few studies that examine the intricacies of caregiving for people with spinal cord injuries. The purpose of this study was to identify issues specific to family caregivers of veterans with spinal cord injuries and develop a relevant, culturally appropriate instrument to assess caregiver distress and/or benefit. Family caregivers of veterans from three geographically diverse sites (Richmond, Virginia, Boston, Massachusetts, and Denver, Colorado) were recruited to participate in focus groups discussing caregiving issues. Twelve focus groups with a total of 59 participants were completed. A significant delay occurred due to an originally committed site dropping from the study and necessitated replacement by the Boston site. Pilot testing of the newly developed instrument was conducted, however, the sample size was smaller than needed for full pilot testing. A future study with a larger sample will be needed to verify the pilot testing results.					
15. SUBJECT TERMS spinal cord injury, veterans, caregivers					
16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT UU	18. NUMBER OF PAGES 19	19a. NAME OF RESPONSIBLE PERSON USAMRMC
a. REPORT U	b. ABSTRACT U	c. THIS PAGE U			19b. TELEPHONE NUMBER (include area code)

TABLE OF CONTENTS	PAGE
Introduction.....	4
Body.....	5
Key Research Accomplishments.....	10
Reportable Outcomes.....	10
Conclusion.....	10
References.....	10
Appendices.....	11

INTRODUCTION

Background: Spinal cord injury (SCI) often results in physical limitations such that receiving assistance from others is critical to maintaining health and facilitating full societal integration. In the general population, almost 70% of people with SCI receive some form of assistance and support from family members. Similarly, the availability of family caregiving is crucial to most veterans with SCI, but there is little research addressing the topic, and no appropriate and available method to comprehensively assess the strengths of and burdens on family caregivers. In the years following rehabilitation, people with SCI will have an increasing need for help as they age. With advancements in quality of care and the fact that the average age of all people living with SCI is over 45 and at least one-fourth have been injured for 20 or more years, the number of people with SCI who require home-based assistance will only increase in the coming years. This is particularly relevant for the veteran population, which is reported to be older, on average, than the general population of people with SCI.

Research Problem: When family caregivers are unable to cope effectively with all role responsibilities, the health and well-being of the care recipient also may be jeopardized. Ultimately, the inability to continue providing care because of declining physical or emotional health may lead to institutionalization of the care recipient. While institutionalization may be considered an acceptable option for frail elderly individuals who have numerous medical and cognitive impairments, people with SCI are likely to be younger and have many years of life ahead of them, and thus may find institutionalization unacceptable. Clearly, the health and well-being of the caregiver is an essential component that helps enable the person with SCI to function as independently as possible and participate in society. A qualitative approach takes advantage of the rich information provided by those living the experience of caregiving and SCI, enabling us to learn what matters most to these caregivers and can help inform the development of an instrument that is relevant to this unique population of family caregivers to veterans with SCI. In better assessing the issues facing family caregivers, we have the potential to address their health and emotional needs and thus positively impact the function, wellness and overall quality of life for veterans who have sustained SCI during or after their years of service.

Specific Aims: The goal of this project is to explicate the specific issues related to caregiving in SCI and develop a relevant and culturally appropriate instrument to assess caregiver distress and/or benefit in SCI. The development of an appropriate measurement tool will help clinicians and service providers better target their interventions, with the goal of improving the support system for veterans with SCI and their family caregivers, and thereby improving long-term outcomes for those veterans with SCI.

Study Design: The proposed will first entail a qualitative design that will involve focus groups of family caregivers of veterans with SCI drawn from three VA study sites. At least 5 focus groups of up to 7 participants at each site will be the minimum necessary to identify the relevant issues and themes. Audiotapes of the focus groups will be transcribed verbatim and analyzed using NVivo-8 qualitative analyses software. Coding will be conducted by three researchers to identify themes that will be used to design a relevant and culturally sensitive instrument to assess caregiver distress and benefit in SCI. Results of this study will be disseminated to relevant stakeholders via presentations and publications.

By the end of this study, the field will have definitive information about the issues facing caregiving family members to veterans with SC and will have a new instrument to assess SCI caregiver distress and benefit in this unique military population.

Impact: The proposed study has a high degree of relevance for veterans with SCI and their family members due to the current lack of information in this area. The knowledge gained from this research will inform clinicians as they work with families early during the SCI rehabilitation process and in the years beyond, enabling them to have a more relevant means of assessing SCI caregiving issues. Without an appropriate psychometrically sound measure of caregiving, the effectiveness of new interventions to help family caregivers cannot be assessed. The proposed qualitative and quantitative methods will provide that needed SCI-specific measure. Finally, we anticipate the study ultimately will benefit veterans with SCI themselves, as it has been noted that erosion in the health and well-being of the primary caregiver may lead to the development of expensive and preventable secondary complications in the person with SCI.

BODY

Objective 1 – Identify participants and conduct focus groups/interviews 1-36)

Task	Activities	Months	Status
1a:	Schedule and conduct collaborator teleconferences and local project site team meetings.	1-36	Completed
1b:	Obtain IRB approval from each study site	1-6	Received from Richmond and Denver, still waiting on IRB approval from Seattle. Personnel changes in Seattle have delayed this process but as of September 2013 IRB approval is expected within 30 days 2013 update: Notified by Seattle that the IRB is understaffed and not approving outside projects at this time. Seattle has withdrawn from the study. <u>2014 update:</u> West Roxbury VA in Boston has agreed to come onto the study and as of this date we are still in the IRB process. A one-year no-cost extension is being requested and we anticipate being able to complete Boston focus groups in early 2015 and complete all study activities by 9-30-15. 2015 update: Complete

1c:	Identify study subjects	6-12	Richmond – completed Denver – completed 2015 update: Boston - completed
1d:	Mail invitations to potential participants - A letter to the individual with SCI will explain the purpose of the study and ask them to nominate one family member who provides personal assistance to them. Identified individuals will be invited to participate in a focus group to discuss his or her caregiving experiences. Participants will receive \$60.00 to thank them for their time and compensate travel	6-12	Richmond – completed Denver – completed 2015 update: Boston - completed
1e:	Update literature review – the existing literature review used to prepare this proposal will be updated quarterly during the first year of the project to identify any new information and themes regarding caregiving	1-12	Completed
1f:	Conduct focus groups/interviews - The PI (Charlifue) will lead each focus group at all sites along with a local facilitator	7-15	Richmond – 5 groups completed Denver – 2 groups have been completed; anticipate 2 more groups to be scheduled 2013 update – no further word from Denver regarding additional groups 2014 update: The site PI and research assistant in Denver are no longer involved with the study. No further activities anticipated from Denver. 2015 update: Boston – 5 focus groups were completed
1g:	Identify missing topics on existing caregiver instrument (CBI, described in Project Narrative)	7-15	To be completed when all focus groups convened and transcripts analyzed 2015 update: Complete – see section below

Objective 2 – Analyze qualitative data

Task	Activities	Months	Status
2a:	Transcribe audiotaped sessions	7-18	Richmond being done currently – 2014 update – transcription of all Richmond and both Denver groups completed 2015 update: All focus groups from all three sites were transcribed – -

			complete
2b:	Export data to NVivo 8	7-18	Pending completion of transcription 2014 update – in progress 2015 update - complete
2c:	Perform qualitative analysis - Qualitative on-going analysis of focus group and individual interviews by the PI and two Research Assistants at Craig Hospital	7-21	Pending completion of 2b 2014 update – in progress 2015 update – complete although this took significantly longer than anticipated.
2d:	Maintain codebook to document the coding criteria for particular thematic codes and document the sequence of analysis decisions	1-21	Pending completion of 2b 2014 update – in progress 2015 update - complete

Objective 3: Develop a relevant and culturally sensitive instrument to assess caregiver distress and/or benefit in SCI:

Task	Activities	Months	Status
3a:	Identify and operationalize themes/topics	7-24	Complete
3b:	Review of questions by focus group participants questions. This will be performed by mailing a packet with the first draft of the questionnaire as well as a stamped return envelope with instructions to rate the questions on importance, relevance, and cultural applicability. Participants will receive \$20.00 to thank them for their input	21-24	Pending completion of 2b 2014 update: only those questions unique to the veteran caregiver group will need to undergo additional review by participants. 2015 update: additional questions identified in the veteran group have been added to the existing civilian instrument developed by this PI for a study funded by National Institute on Disability and Rehabilitation Research. None of the questions were unique to the veteran group – all had been identified in the civilian group but some were dropped in analysis of the civilian data. It is felt that additional review was not necessary as these questions underwent evaluation previously and the time constraints were such that it was felt this step could be eliminated.

3c:	Refine questions and develop pilot instrument	21-24	Partially completed; additional questions to be added after all focus groups completed 2014 update – will use same questions as developed in civilian caregiver study where themes are the same as with the veteran caregivers. New questions will be limited to themes exclusive to veteran caregivers (anticipate few) 2015 update – complete (see attached)
3d:	Cognitive testing of the proposed questions. The cognitive interviews will be administered either in person or by telephone by the Craig team. Individuals will be paid \$25.00 for their participation in the cognitive interviews	25-27	2014 update: will be done after 3c completed 2015 update: See above – this step felt to be redundant
3e:	Revise questions based on cognitive testing and finalize first draft	25-27	2014 update: will be done after 3d completed 2015 update: NA – see above

Objective 4: Conduct pilot test of newly developed instrument

Task	Activities	Months	Status
4a:	Pilot test instrument. Participants will be asked to review and sign a newly approved consent form (submitted by each site to their respective IRB), complete the questionnaire and return it to the site Co-Investigator (then forwarded to the PI) in a provided stamped return envelope. A \$7.00 check will be included in the mailing as a “thank you” to participants	25-30	2014 update: Will be done in 2015 after Boston focus groups and all analysis completed and new questions incorporated. 2015 update: Instrument has been sent to Boston VA for pilot testing. Awaiting their IRB approval and then will need HRPO approval before starting pilot. 2017 update: Pilot testing completed with 80 respondents from the Boston VA site.
4b:	Enter and clean pilot test data - Data from the pilot testing will be entered into a Microsoft Access® database and checked for accuracy using a 10% quality control sample. Any discrepancies noted in the 10% sample will necessitate full double entry of all data to ensure full accuracy	27-30	2014 update: To follow above 2015 update: As above 2017 update: Completed and verified as accurate.
4c:	Analyze pilot test data	30-33	2015 update: As above 2017 update: See attached analysis report. Due to smaller than needed numbers of respondents, the pilot testing

			results will need to be verified in a larger sample at a future date.
--	--	--	--

4d:	Prepare final caregiver assessment instrument. Based on the analysis in 4c above, a final draft of a SCI caregiver assessment instrument will be prepared for a validation study in a future project	34-36	2014 update: To follow above 2015 update: As above 2017 update: Instrument for further validation is attached.
-----	--	-------	---

Objective 5: Dissemination

5a:	Prepare manuscript of qualitative findings	27-36	2014 update: Will be prepared before 9-30-15 2015 update: Will be prepared before 9-30-16 2017 update: First draft in process
5b:	Presentations at professional meetings	18-24 and 30-36	2013 update: Presentation at State of the Science conference on Families of Injured, Ill and Wounded Veterans, September 2013 2014 update: Anticipate presentation in 2015 at DoD sponsored conference 2015 update: Will submit to 2016 DoD sponsored conference 2017 update: Not accepted at 2016 DoD sponsored conference; data presented at Canadian Spinal Cord Injury Conference focusing on veterans issues November of 2017.

ADDITIONAL INFORMATION: The VA sites required that the PI (Charlifue) have a WOC in order to conduct the focus groups on site. Acquisition of the WOC took approximately 10 months to obtain and focus groups had to be postponed until the WOC was in hand.

UPDATE Sept 2013: due to delays in IRB approvals (and in some cases, inability to obtain IRB approval) a contingency plan to move forward with data from the 7 existing focus groups was discussed with project officer.

UPDATE Sept 2014: Boston required a new WOC pertinent to their site. This process (bringing Boston on board) has been in process since March of 2014. Anticipate all paperwork and contract with Boston to be completed by end of October 2014, IRB submission in Boston in November of 2014. Contract with Boston cannot be signed until no-cost extension approved.

UPDATE Sept 2015 (Jan 2016): Due to delays in securing a replacement site, a one-year no-cost extension was requested.

UPDATE December 2017: See below.

KEY RESEARCH ACCOMPLISHMENTS

No key research accomplishments to report as of yet other than the objectives achieved as noted above.

UPDATE Sept 2014 – 7 focus groups completed (5 in Richmond, 2 in Denver). 41 participants; mean age 59 years, 95% female; 51% Caucasian; 78% spouse; mean years of caregiving 11.8 (range <1-52); mean hours per day caregiving 9.9. Themes appear similar to those identified in a study of civilian caregivers with some positives noted, outweighed by negatives. Positive themes include change in self-awareness, closeness of family, increased compassion, feeling appreciated, still having family member with them. Negatives include lack of time for self, physical and emotional exhaustion, lack of spontaneity, lack of understanding from others, lack of appreciation from family members, unexpected illnesses, dissatisfaction with hired carers and agencies, strain on family relationships. Caregivers also report changes in work (ability to maintain jobs or need to reduce hours), finances, limited travel and leisure, lack of privacy, loss of friendships.

UPDATE Sept 2015 (Jan 2016): 12 focus groups completed – 7 as above plus 5 at West Roxbury VA near Boston. Total from all sites 59 participants; mean age 60 years; 97% female; 64% Caucasian; 73% spouse; mean years of caregiving 12.6 (range <1-52); mean hours per day caregiving 9.6. Themes as above. Topic saturation achieved.

UPDATE December 2017: Instrument developed including new questions from focus groups of caregivers to veterans with SCI. Details of instrument development and initial validation attached.

REPORTABLE OUTCOMES

UPDATE Sept 2015 (Jan 2016): Instrument has been developed. Will need additional analysis based on input from participants at the West Roxbury VA. Anticipate analysis summer of 2016 with final instrument available by end of grant period September 2016.

UPDATE December 2017: See attached analysis and instrument information.

CONCLUSIONS

Due to a smaller than necessary sample for full instrument validation, further funding from a variety of sources will be sought for full validation.

REFERENCES

None

APPENDICES

See attached analysis information.

Rasch Analysis

Advanced psychometric methodology using Rasch analysis was previously used to develop the C²ARE tool in a sample of civilians with spinal cord injury (SCI). Various statistical strategies using classical test theory such as factor analysis, Cronbach's alpha, point biserial correlations, and computing a raw total score are commonly used to develop instruments for psychosocial research. These techniques are used to evaluate the strength of the inferences drawn from instruments and to compute respondents' performances. Rasch analysis is an advanced psychometric technique that was developed to improve the precision with which researchers can develop instruments, monitor instrument quality, and compute respondents' performances. Rasch analysis has helped researchers think in more sophisticated ways with respect to the constructs (variables) they wish to measure. One major advantage Rasch analysis has over classical testing theory is that it allows researchers to make use of raw test scores and ordinal rating scale data to compute linear "person measures" which more accurately express an individual respondents' performance on a linear scale that accounts for the unequal difficulties across all items. Rasch techniques involve correction for a number of psychometric issues (e.g., rating scales are ordinal, not all survey items mark the same part of the variable) so that accurate person measures can be computed. This transformation of ordinal data to interval level scaling makes these data more appropriate for subsequent parametric statistical analyses.

Development of C²ARE Tool – Civilian Sample

The C²ARE tool was previously developed using Rasch analyses in a sample of 151 caregivers of persons with SCI. The initial survey used to develop the C²ARE tool consisted of 117 items used to measure caregiver rewards and efforts. These items were all measured on a 6 point ordinal scale (1= always, 2 = very often, 3 = sometimes, 4 = rarely, 5 = very rarely, 6 = never).

Development of the C²ARE Tool was completed based on three main steps, where these steps were to some degree executed in tandem. In the first step, the five previously identified subscales were examined independently and tested for unidimensionality. Unidimensionality indicates the subscale is capturing the desired underlying construct. Rasch principle component analysis was used to test for patterns in the residuals. Eigenvalues (EV) of the first contrast greater than 2.0 suggest that the items considered do not capture a single underlying construct. In the second step item fit within each subscale was examined. If an item adheres to the expectations of the Rasch model, then infit/outfit values less than 1.5 are observed. In the third step, item characteristic curves (ICC) were examined to assess for step disorder within each item. If step disorder is absent then categories within items, expressed in the form ICC curves, should be distinct and demonstrate a monotonic increasing pattern. If ICCs show categories that do not adhere to this pattern (show step disorder) then categories are subsequently collapsed accordingly until the preferred pattern is achieved.

Rasch analyses of these data resulted in an instrument with 26 items and 5 subscales conceptually labeled as Physical Health, Emotional Health, Control/Confidence, Social Support and Time Commitment. The table below summarizes these 26 items.

Table 1: C²ARE Tool developed from Civilian sample

Physical Health
I'm not getting enough sleep
I feel I am more likely to have an injury because of caregiving
I have physical pain because of caregiving
I get as much exercise as I want to
I take good care of my own health issues
Emotional Health
I feel emotionally drained due to caring for my family member with SCI
I feel completely overwhelmed as a caregiver
I feel stressed because of being a caregiver
I feel angry because I have to be a caregiver
I feel depressed because of my caregiving responsibilities
I feel trapped due to being a caregiver
Control/Confidence
I can problem-solve issues that develop related to caregiving
Being a caregiver makes me feel useful
I am able to successfully make my own needs known to my care receiver
I am comfortable saying "no" to my family member with SCI when I need to
I feel I have no control over my life
Social Support
I feel resentful toward other relatives who could but do not help
There are family members I can talk to when I have important decisions to make
I find it hard to ask for help from others
I have someone I can talk to about my concerns/frustrations related to caregiving
I feel alone with no one to turn to
Time Commitment
I have no spare time to do things that I want to do because of caregiving
I have as much freedom as I want
I don't do things I want to because of caregiving responsibilities
I make sure I have personal time for myself
I feel like I don't have a minute's break from my caregiving chores

A detailed summary of the results from the Rasch analysis based on the civilian sample is provided in Table 2. For each subscale, the items are listed in terms of their endorseability, where the most difficult item to endorse is listed first and the easiest item to endorse listed last. Joint maximum likelihood estimation was used to calculate logit estimates and their corresponding standard errors. The corresponding value of the item on the logit scale is reported next to each item in parentheses, along with its associated standard error. All items within each dimension (subscale) demonstrated acceptable model fit indicated by infit/outfit estimates less than 1.5. The item reliability index of each subscale is also provided along with the EV of the first contrast. Item index values greater than 0.8 are traditionally deemed acceptable and suggests the item hierarchy within each subscale is likely to hold in a different sample of similar individuals. Eigenvalues of the first contrast were all less than 2.0 suggesting the items contained within each subscale capture a single underlying contrast. Examination of the ICCs indicated at least some level of category step disorder across dimensions. Thus, categories were collapsed and the scale was reduced from 6 categories to 4 categories: 1= always/very often, 2/3 = sometimes, 4/5 = rarely, 6 = never.

Table 2: Summary of Rasch Analysis – DEVELOPMENT (Prior sample)

PH Item Reliability = 0.97 EV 1 st Contrast = 1.7	EH Item Reliability = 0.98 EV 1 st Contrast = 1.6	CC Item Reliability = 0.95 EV 1 st Contrast = 1.7	SS Item Reliability = 0.98 EV 1 st Contrast = 1.9	TC Item Reliability = 0.97 EV 1 st Contrast = 1.5
Sleep (1.69, 0.15)	Drained (1.96, 0.21)	Nocontrol (1.13, 0.14)	HardtoAsk (1.77, 0.15)	Sparetime (1.35, 0.21)
Pain (-0.13, 0.14)	Stressed (1.91, 0.22)	SayNo (0.32, 0.15)	Alone (0.23, 0.14)	Candoaswant (1.23, 0.21)
Exercise (-0.25, 0.14)	Overwhelmed (-0.10, 0.19)	Ownneeds (-0.26, 0.16)	Resent (-0.57, 0.13)	Freedom (0.41, 0.20)
Injlikely (-0.27, 0.14)	Trapped (-0.57, 0.19)	Useful (-0.29, 0.15)	Talktoother (-0.33, 0.14)	NoBreak (-1.15, 0.20)
Good Care (-1.07, 0.15)	Depressed (-1.42, 0.18)	Problemsolve (-0.91, 0.16)	TalkFam (-1.10, 0.14)	PersonalTime (-1.84, 0.19)
	Angry (-1.79, 0.18)			

Validation of C²ARE Tool in a Veteran Population

This study sought to further develop the C²ARE tool in a sample of caregivers of veterans with SCI. A survey including 48 items was administered to a sample of 80 caregivers of veterans with SCI. This survey included the 26 items previously identified in the development of the C²ARE Tool in the civilian population along with an additional 22 items that were developed after the veteran caregiver focus group information was evaluated. Each item was measured on a 4 point ordinal scale (1= very often, 2 = sometimes, 3 = rarely, 4 = never). Each of the 22 new items was classified into one of the 5 previously identified subscales by the PI (Charlifue). One item (Q43^R = Having good health benefits for my loved one with SCI is a relief) did not seem to fit well into any of the subscales conceptually. In addition over 92% of the subjects endorsed this item as “Very Often” suggesting it will not contribute much to this instrument. Thus, this item was not considered for addition to any of the subscales. First, the 26 items previously identified were selected and fit to the same Rasch Model that was developed in the civilian population. These are all summarized as Model A in the subsequent sections. Next, the additional items for each subscale were added and model fit was assessed; these are indicated by Model B. Finally, steps were taken to remove items that showed poor infit/outfit and item category misfit. These are summarized as Models C, D, etc. The best fitting set of items was then selected and further summarized.

Physical Health Rasch Analysis

Table 3: Physical Health Model Fit Summary		
	Model A	Model B ***
Items	[1, 9 ^R , 19, 23 ^R , 39]	+ [27 ^R , 36]
Person Separation	1.49	1.68
Person Reliability	0.69	0.74
Item Separation	3.94	3.68
Item Reliability	0.94	0.93
EV 1 st Contrast	1.60	1.99
Item Infit Range	(0.67, 1.53)	(0.61, 1.46)
Item Outfit Range	(0.69, 1.50)	(0.63, 1.35)
High Item infit/outfit	Q9 ^R	
Category Step Disorder		

^R indicates items that were reverse coded

Model A includes items [1, 9^R, 19, 23^R, 39]

Model B includes items [1, 9^R, 19, 23^R, 39, 27^R, 36]

Eigenvalues (EV) of the first contrast greater than 2.0 suggest that the items considered do not capture a single underlying construct

Model B is the best fitting (EV < 2, maximum item and person separation and reliability, item reliability > 0.8, item infit and outfit < 1.5, no evidence of category step disorder with any of the items). The table below summarizes the 7 items for the Physical Health subscale based on Model B. The items are listed in terms of their endorseability, where the most difficult item to endorse is listed first and the easiest item to endorse listed last. Joint maximum likelihood estimation was used to calculate logit estimates and their corresponding standard errors. The corresponding value of the item on the logit scale is reported along with its associated standard error.

Table 4: Physical Health Logit Estimates			
Item number	Estimate	SE	Full Question
Q27 ^R	0.77	0.16	I feel I am more physically fit due to being a caregiver
Q1	0.71	0.16	I'm not getting enough sleep
Q19	0.22	0.15	I have physical pain because of caregiving
Q39	0.00	0.15	I feel I am more likely to have an injury because of caregiving duties
Q9 ^R	-0.14	0.15	I get as much exercise as I want to
Q36	-0.32	0.15	I neglect my own health issues because of caregiving responsibilities
Q23 ^R	-1.24	0.17	I take good care of my own health issues

^R indicates items that were reverse coded

Emotional Health Rasch Analysis

Table 5: Emotional Health Model Fit Summary					
	Model A ***	Model B	Model C	Model D	Model E
Items	[2, 10, 20, 28, 42, 50]	+ [35 ^R , 37 ^R , 45, 47]	- [37 ^R]	- [35 ^R]	- [47]
Person Separation	3.00	2.29	2.51	2.65	2.85
Person Reliability	0.90	0.84	0.86	0.88	0.89
Item Separation	4.86	2.60	3.07	3.46	4.00
Item Reliability	0.96	0.87	0.90	0.92	0.94
EV 1 st Contrast	1.55	2.68	2.02	1.96	1.75
Item Infit Range	(0.66, 1.06)	(0.45, 2.63)	(0.48, 2.01)	(0.51, 2.18)	(0.56, 1.64)
Item Outfit Range	(0.68, 1.43)	(0.45, 3.58)	(0.52, 3.04)	(0.49, 2.27)	(0.53, 1.67)
High Item infit/outfit		Q37 ^R	Q35 ^R , Q47	Q47	Q45
Category Step Disorder					

^R indicates items that were reverse coded

*** indicates best fitting model selected

Model A includes items [2, 10, 20, 28, 42, 50] (civilian questions)

Model B includes items [2, 10, 20, 28, 42, 50, 35^R, 37^R, 45, 47] (added new questions)

Model C includes items [2, 10, 20, 28, 42, 50, 35^R, 45] (removed Q37^R)

Model D includes items [2, 10, 20, 28, 42, 50, 45] (removed Q35)

Model E includes items [2, 10, 20, 28, 42, 50, 45] (removed Q47)

(removing Q45 gets us back to Model A)

Model A looks to be the best fitting (EV < 2, maximum item and person separation and reliability, item reliability > 0.8, item infit and outfit < 1.5, no evidence of category step disorder with any of the items). The table below summarizes the 6 items for the Emotional Health subscale based on Model A. The items are listed in terms of their endorseability, where the most difficult item to endorse is listed first and the easiest item to

endorse listed last. Joint maximum likelihood estimation was used to calculate logit estimates and their corresponding standard errors. The corresponding value of the item on the logit scale is reported along with its associated standard error.

Table 6: Emotional Health Logit Estimates			
Item number	Estimate	SE	Full Question
Q42	1.37	0.24	I feel stressed because of being a caregiver
Q10	1.19	0.24	I feel emotionally drained due to caring for my family member with SCI
Q2	0.41	0.24	I feel completely overwhelmed as a caregiver
Q28	0.06	0.24	I feel depressed because of my caregiving responsibilities
Q20	-0.69	0.24	I feel trapped due to being a caregiver
Q50	-2.34	0.25	I feel angry because I have to be a caregiver

^R indicates items that were reverse coded

Control/Confidence Rasch Analysis

Table 7: Control/Confidence Model Fit Summary				
	Model A	Model B	Model C	Model D ***
Items	[3 ^R , 11 ^R , 21 ^R , 29 ^R , 41]	+ [7, 14, 24 ^R , 25, 26]	- [11 ^R]	- [7]
Person Separation	0.95	1.48	1.54	1.50
Person Reliability	0.48	0.69	0.70	0.69
Item Separation	4.59	6.01	6.24	5.64
Item Reliability	0.95	0.97	0.97	0.97
EV 1 st Contrast	1.68	1.82	1.80	1.88
Item Infit Range	(0.78, 1.22)	(0.70, 1.42)	(0.67, 1.48)	(0.69, 1.36)
Item Outfit Range	(0.77, 1.38)	(0.68, 1.55)	(0.66, 1.61)	(0.66, 1.48)
High Item infit/outfit		Q11 ^R , Q7	Q7	
Category Step Disorder	Q11 ^R	Q7	Q7	

^R indicates items that were reverse coded

*** indicates best fitting model selected

Model A includes items [3^R, 11^R, 21^R, 29^R, 41] (civilian questions)

Model B includes items [3^R, 11^R, 21^R, 29^R, 41, 7, 14, 24^R, 25, 26] (added new questions)

Model C includes items [3^R, 21^R, 29^R, 41, 7, 14, 24^R, 25, 26] (removed Q11^R)

Model D includes items [3^R, 21^R, 29^R, 41, 14, 24^R, 25, 26] (removed Q7)

Model D looks to be the best fitting (EV < 2, item infit/outfit < 1.5, acceptable item and person separation and reliability, item reliability > 0.8, no evidence of category step disorder with any of the items). While Model D did not provide the maximum item and person separation and reliability compared to Models B, these indices were similar and Model D showed improvements in item infit/outfit and category step disorder. The table below summarizes the 8 items for the Control/Confidence subscale based on Model D. The items are listed in terms of their endorseability, where the most difficult item to endorse is listed first and the easiest item to endorse listed last. Joint maximum likelihood estimation was used to calculate logit estimates and their corresponding standard errors. The corresponding value of the item on the logit scale is reported along with its associated standard error.

Table 8: Control/Confidence Logit Estimates			
Item number	Estimate	SE	Full Question
Q14	1.75	0.16	I feel I'm the only one who can take care of my family member the right way
Q41	0.41	0.15	I feel I have no control in my life
Q21 ^R	0.40	0.15	I am comfortable saying "no" to my family member with SCI when I need to
Q25	0.39	0.15	I feel I have lost who I am due to caregiving
Q26	0.07	0.15	I have fears that I can't provide the right care for my family member with SCI
Q3 ^R	-0.34	0.15	I am able to successfully make my own needs known to my care receiver
Q24 ^R	-1.07	0.18	My family member with SCI makes me feel useful and appreciated
Q29 ^R	-1.62	0.21	I can problem-solve issues that develop related to caregiving

^R indicates items that were reverse coded

Social Support Rasch Analysis

Table 9: Social Support Model Fit Summary				
	Model A	Model B	Model C	Model D ***
Items	[4 ^R , 12, 30, 40 ^R , 49]	+ [6, 8, 15 ^R]	- [30]	- [4 ^R]
Person Separation	1.00	1.47	1.47	1.53
Person Reliability	0.50	0.68	0.68	0.70
Item Separation	4.82	4.69	4.26	4.01
Item Reliability	0.96	0.96	0.95	0.94
EV 1 st Contrast	1.64	1.73	1.71	1.67
Item Infit Range	(0.84, 1.23)	(0.56, 1.39)	(0.57, 1.25)	(0.58, 1.15)
Item Outfit Range	(0.78, 2.25)	(0.58, 1.84)	(0.65, 1.24)	(0.61, 1.22)
High Item infit/outfit	Q30	Q30		
Category Step Disorder		Q4 ^R	Q4 ^R	

^R indicates items that were reverse coded

*** indicates best fitting model selected

Model A includes items [4^R, 12, 30, 40^R, 49] (civilian questions)

Model B includes items [4^R, 12, 30, 40^R, 49, 6, 8, 15^R] (added new questions)

Model C includes items [4^R, 12, 40^R, 49, 6, 8, 15^R] (removed Q30)

Model D includes items [12, 40^R, 49, 6, 8, 15^R] (removed Q4^R)

Model D looks to be the best fitting (EV < 2, item infit/outfit < 1.5, acceptable item and person separation and reliability, item reliability > 0.8, no evidence of category step disorder with any of the items). While Model D did not provide the maximum item separation and reliability compared to Models A-C, these indices were similar and Model D showed improvements in item infit/outfit and category step disorder. The table below summarizes the 6 items for the Social Support subscale based on Model D. The items are listed in terms of their endorseability, where the most difficult item to endorse is listed first and the easiest item to endorse listed last. Joint maximum likelihood estimation was used to calculate logit estimates and their corresponding standard errors. The corresponding value of the item on the logit scale is reported along with its associated standard error.

Table 10: Social Support Logit Estimates			
Item number	Estimate	SE	Full Question
Q6	1.30	0.17	I feel that others don't understand the difficulties involved with being a caregiver
Q8	0.20	0.15	I have financial concerns as a results of my need to be a caregiver
Q15 ^R	-0.04	0.15	I feel I have friends who I can count on to help me
Q49	-0.31	0.15	I feel alone with no one to turn to
Q12	-0.38	0.15	I feel resentful towards other relatives who could help but do not
Q40 ^R	-0.77	0.16	I have someone I can talk to about my concerns/frustrations related to caregiving

^R indicates items that were reverse coded

Time Commitment Rasch Analysis

Table 11: Time Commitment Model Fit Summary					
	Model A	Model B	Model C	Model D	Model E ***
Items	[5, 13 ^R , 22, 31, 48 ^R]	+ [16, 17 ^R , 18, 34, 38, 44 ^R]	- [48 ^R]	- [34]	- [17 ^R]
Person Separation	2.20	2.72	2.66	2.63	2.66
Person Reliability	0.83	0.88	0.88	0.87	0.88
Item Separation	4.18	5.12	5.00	5.02	5.46
Item Reliability	0.95	0.96	0.96	0.96	0.97
EV 1 st Contrast	1.63	1.99	1.95	1.96	2.05
Item Infit Range	(0.76, 1.50)	(0.64, 1.39)	(0.68, 1.71)	(0.64, 1.52)	(0.71, 1.45)
Item Outfit Range	(0.75, 1.72)	(0.59, 2.48)	(0.64, 1.70)	(0.62, 1.61)	(0.68, 1.17)
High Item infit/outfit	Q48 ^R	Q48 ^R	Q34	Q17 ^R	
Category Step Disorder		Q48 ^R			

^R indicates items that were reverse coded

*** indicates best fitting model selected

Model A includes items [5, 13^R, 22, 31, 48^R] (civilian questions)

Model B includes items [5, 13^R, 22, 31, 48^R, 16, 17^R, 18, 34, 38, 44^R] (added new questions)

Model C includes items [5, 13^R, 22, 31, 16, 17^R, 18, 34, 38, 44^R] (removed Q48^R)

Model D includes items [5, 13^R, 22, 31, 16, 17^R, 18, 38, 44^R] (removed Q34)

Model D includes items [5, 13^R, 22, 31, 16, 18, 38, 44^R] (removed Q17^R)

Model E looks like the best selection although the EV is just slightly larger than 2 (item infit/outfit < 1.5, acceptable item and person separation and reliability, item reliability > 0.8, no evidence of category step disorder with any of the items). While Model E did not provide the maximum item separation and reliability compared to Models B, these indices were similar and Model E showed improvements in item infit/outfit and category step disorder. The table below summarizes the 7 items for the Time Commitment subscale based on Model E. The items are listed in terms of their endorseability, where the most difficult item to endorse is listed first and the easiest item to endorse listed last. Joint maximum likelihood estimation was used to calculate logit estimates and their corresponding standard errors. The corresponding value of the item on the logit scale is reported along with its associated standard error.

Table 12: Time Commitment Logit Estimates			
Item number	Estimate	SE	Full Question
Q16	2.52	0.25	I think caregiving is a 24/7 job
Q22	0.79	0.21	I don't do things I want to do because of caregiving responsibilities
Q31	0.18	0.21	I have no spare time to do things that I want to do because of caregiving
Q18	-0.02	0.21	I feel torn between my duties as a caregiver and other responsibilities
Q13R	-0.90	0.20	I have as much freedom as I want
Q5	-1.19	0.20	I feel like I don't have a minute's break from my caregiver chores
Q44	-1.39	0.20	Caregiving takes time away from other family member and their needs

^R indicates items that were reverse coded

A summary of the 34 questions resulting from the Rasch Analysis are in the table below. The Rasch analysis conducted here was based on a sample of only 80 caregivers of veterans with SCI and should be validated in a much larger caregiver sample (> 250). The full instrument to be validated appears on the following page.

Table 31: C²ARE Tool developed from Veteran sample

Physical Health
I feel I am more physically fit due to being a caregiver
I'm not getting enough sleep
I have physical pain because of caregiving
I feel I am more likely to have an injury because of caregiving duties
I get as much exercise as I want to
I neglect my own health issues because of caregiving responsibilities
I take good care of my own health issues
Emotional Health
I feel stressed because of being a caregiver
I feel emotionally drained due to caring for my family member with SCI
I feel completely overwhelmed as a caregiver
I feel depressed because of my caregiving responsibilities
I feel trapped due to being a caregiver
I feel angry because I have to be a caregiver
Control/Confidence
I feel I'm the only one who can take care of my family member the right way
I feel I have no control in my life
I am comfortable saying "no" to my family member with SCI when I need to
I feel I have lost who I am due to caregiving
I have fears that I can't provide the right care for my family member with SCI
I am able to successfully make my own needs known to my care receiver
My family member with SCI makes me feel useful and appreciated
I can problem-solve issues that develop related to caregiving
Social Support
I feel that others don't understand the difficulties involved with being a caregiver
I have financial concerns as a results of my need to be a caregiver
I feel I have friends who I can count on to help me
I feel alone with no one to turn to
I feel resentful towards other relatives who could help but do not
I have someone I can talk to about my concerns/frustrations related to caregiving
Time Commitment
I think caregiving is a 24/7 job
I don't do things I want to do because of caregiving responsibilities
I have no spare time to do things that I want to do because of caregiving
I feel torn between my duties as a caregiver and other responsibilities
I have as much freedom as I want
I feel like I don't have a minute's break from my caregiver chores
Caregiving takes time away from other family member and their needs